2025 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia.

Executive Summary

Attached please find the 2025 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia (Council) prepared for the Governor and the New York State Legislature. The report covers calendar years 2023-2024 and includes an overview of the Council and its purpose, key definitions and demographic information, an update on issues that affect the lives of those impacted by Alzheimer's and dementia as well as the services they receive, a comprehensive update on the status of federal and state initiatives, a description of initiatives managed by various NYS agencies, and a series of goals and recommendations for 2025 and 2026.

The New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia was established pursuant to Chapter 58, Part B, section 24 of the Laws of 2007, and as cited in Public Health Law Section 2004-a. The Council was formed to facilitate interagency planning and policymaking, review specific agency initiatives for their impact on services related to the care of persons living with Alzheimer's disease and related dementia (ADRD) and their families, and provides a continuing forum for concerns and discussions related to the formulation of a comprehensive state policy for Alzheimer's disease and related dementia. The complete list of Council members can be found at the end of the full report (Attachment A).

Dementia is a term that broadly describes a group of symptoms affecting memory, thinking and social abilities. The symptoms interfere with a person's daily life. Dementia isn't one specific disease. Several diseases can cause dementia, including degenerative neurocognitive disorders. Dementia reflects an impairment of brain functioning, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive functioning), behavioral and psychiatric disorders (e.g., depression, agitation), and a decline in an individual's ability to perform activities of daily living (ADL) and function independently.

Alzheimer's disease is the most common form of dementia: 60-80% of individuals with dementia have Alzheimer's disease. Alzheimer's disease is a degenerative and ultimately fatal condition. Currently the exact cause of Alzheimer's disease remains unknown and there is no cure. Traditional treatments may temporarily improve or slow worsening of symptoms. Since 2023, the US Food and Drug Administration (FDA) has granted full approval, of two disease targeting therapies to treat Alzheimer's disease in the early, mild stages. The new medications address the underlying course of Alzheimer's, treating the disease. There are several additional drugs and devices for the treatment of Alzheimer's disease and related dementia currently under review by the US Food and Drug Administration. Continued research to fully understand the biological origins of the disease is critically needed. Researchers have discovered several risk factors directly associated with Alzheimer's disease: older age, family history, heredity, and lifestyle, and as such, individuals can pursue many lifestyle changes to potentially lower their risk of developing Alzheimer's disease and related dementia. Strategies include engaging in physical activity, receiving proper sleep, maintaining a healthy diet, and staying socially and cognitively active. Individuals should also manage chronic conditions to reduce their risk of

developing dementia. Strategies include managing diabetes, blood pressure, and lowering cholesterol levels.

National prevalence data indicates that an estimated 6.9 million Americans, age 65 and older live with Alzheimer's disease; approximately 73% of these individuals are over age 75. Although Alzheimer's disease is typically diagnosed in people over age 65, it is estimated that at least 200,000 Americans between the ages of 30 to 64 are diagnosed with "younger/early onset" dementia. An article published in the Alzheimer's & Dementia: The Journal of Alzheimer's and Dementia, indicates the number of individuals living with Alzheimer's disease in New York State is approximately 426,000. That number is expected to increase. New York State has the second highest prevalence of Alzheimer's disease in the United States. The United States Department of Health and Human Services (HHS) recognizes that Alzheimer's disease and related dementia disproportionately impacts racial and ethnic minorities, individuals with younger onset Alzheimer's disease and related dementia, those with Down syndrome, and women.

The scope of Alzheimer's disease has been difficult to fully project for multiple reasons. These include the following: many people remain undiagnosed because they are unaware of their symptoms or do not share them with their medical providers, medical providers are reluctant to give this diagnosis, there is a shortage of trained medical providers who can diagnose and treat Alzheimer's disease and related dementia, and cultural barriers and stigma discourage individuals from seeking a diagnosis.

The New York State Department of Health, the National Plan to Address Alzheimer's disease, the Alzheimer's Association, and The Healthy Brain Initiative recommend early detection of Alzheimer's disease and related dementia. Early detection is important for the individual living with Alzheimer's disease and related dementia for a number of reasons including, but not limited to: accessing treatments that may slow the progression of the disease, participating in clinical trials, and accessing support services, planning, and preparing for the future while they still have the capacity to do so. The National Institute on Health (NIH) indicate that scientists are making significant gains in identifying new ways to diagnose, treat, and prevent Alzheimer's disease and related dementia. These advances are made possible only through people participating in clinical trials. Participation rates in Alzheimer's disease and related dementia clinical trials are very low.

Millions of Americans are informal caregivers who provide unpaid care for individuals with Alzheimer's disease and related dementia. Nationally, informal caregivers for individuals with Alzheimer's disease and related dementia Alzheimer's disease and related dementia provide an estimated 18.4 billion hours of unpaid care. In New York State, over 543,000 caregivers provided eight hundred and seventy-nine (879) million hours of unpaid care for individuals with Alzheimer's disease and related dementia, valued at nearly 19 billion dollars. The role of an informal caregiver for a person with Alzheimer's disease and related dementia is intensely stressful. Caring for individuals with Alzheimer's disease, especially in the later stages of the disease, can be physically and emotionally demanding.

In 2022, New York State embarked on the Master Plan for Aging (MPA). The Master Plan for Aging is designed to ensure that older adults and individuals of all ages can live healthy, fulfilling lives while aging with dignity and independence.

In September 2023, the New York State Department of Health entered into a 5-year cooperative agreement with the Centers for Disease Control and Prevention (CDC) for the Building Our

Largest Dementia Infrastructure public health program. Annual funding of $450,000 aims to expand activities related to awareness about early detection and diagnosis of Alzheimer's disease and related dementia, brain health and risk reduction strategies, the management of chronic disease comorbidities, and to increase clinical-community linkages.

For 2025 and 2026, the Council has developed a series of recommendations that members will use as both a roadmap for progress and a call for diverse groups to work together to achieve them. This report also identifies the Goals and Recommendations of the Council for calendar year 2025-2026. The goals that drive the recommendations are as follows:

- Goal 1: Enhance public awareness and advance early detection of Alzheimer's disease and all related dementia.
- Goal 2: Improve clinical care of Alzheimer's disease and related dementia.
- Goal 3: Ensure access to housing and supports that promote living in the least restrictive environment and support formal caregivers in these settings.
- Goal 4: Supporting informal caregivers and persons living with Alzheimer's disease and related dementia.
- Goal 5: Address disparities and improve health equity.
- Goal 6: Promote research, prevention, and risk reduction strategies.

Of the aforementioned Goals and Recommendations, the Council has determined the top three priorities for 2025-2026 to include:

1. Risk reduction and early detection/diagnosis of Alzheimer's and related dementia.
2. Increase and support for the direct care workforce.
3. Support informal caregivers of persons living with Alzheimer's disease and related dementia.

The recommendations provide opportunities for government, healthcare, human service professionals and institutions, business, and philanthropies to come together with a common set of goals and activities.

We thank you in advance for your review of this report and consideration of the recommendations.

Questions regarding this report, should be directed to the Bureau of Alzheimer's Disease Program at alz@health.ny.gov.